An integrated model of care for young people with liver disease and transplant

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Keywords: Chronic disease, adolescent health, mental health, transition care, electronic health care, screening.

Suggested Running Title: integrated care for young people chronic disease

Word Count: 4,195

ABSTRACT

Rationale, aims and objectives: Young people (YP) with chronic illness have increased risk of mental health problems. This paper evaluates the feasibility, acceptability and effectiveness of incorporating routine electronic mental health screening into the standard multi-disciplinary healthcare of YP with chronic liver disease and liver transplant.

Methods: 187 YP (mean age 18 years, 53% female) attending routine appointments in a tertiary service in the UK completed mental health screening prior to their clinic appointment. These standardized measures (the 9-item Patient Health Questionnaire [PHQ9] and the 7-item Generalised Anxiety questionnaire [GAD7]) were completed using an informatics system that facilitates routine collection of patient-reported outcomes, with real-time feedback to guide clinical care. Responses are immediately uploaded to medical notes and evaluated by their clinical team. 53 YP completed an additional feasibility measure. YP screening positive were assessed by the clinical team, with appropriate support offered. Level of clinician agreement with screening programme was ascertained by the team's clinical psychologist.

Results: YP reported that completing the electronic screening was acceptable, a positive experience, and that routine mental health screening in this manner would not affect the way they felt about coming to clinic. Clinician judgement corroborated 31 of the 33 YP who screened as positive for anxiety/depression. Screening did not effectively identify all YP warranting psychosocial input.

Conclusions: Screening using electronic measures, with responses uploaded in real-time to medical notes for consultant review, can facilitate the rapid identification of mental health problems in YP with physical health problems, in an acceptable and time/cost-effective way. This should be combined with the support of embedded mental health practitioners within physical healthcare environments.

INTRODUCTION

Young people (YP) are at increased risk of developing mental health problems, with clinically diagnosable mental health problems present in approximately 4% of boys and 6% of girls aged 11-16, increasing to 13% of boys and 10% of girls when behavioural and hyperactivity disorders are included. [5] This risk of mental health problems further increases in YP with chronic illness: meta-analyses report higher rates of depressive and anxiety symptoms when compared with healthy peers [6,7]. In a recent study of 187 YP (aged 16-25 years) with chronic liver disease and liver transplant, 17.7% self-reported clinically diagnosable levels of anxiety/depression. [8]

Increasing numbers of young people (YP) are using health services, due to a growing population, improved survival rates in children with long-term physical conditions (LTC), and inflated risk of developing health problems through injury and risk-taking behaviours relative to other age groups [1,2]. YP with LTC face the same normative life changes and challenges as their healthy peers but with additional challenges posed by their condition and the transitions from paediatric to adult health services. [2] These interrelated changes lead to elevated medication non-adherence and disengagement from services, resulting in poor physical health outcomes. [1] Organ transplant studies demonstrate high rates of non-adherence and subsequent loss of the grafts during adolescence and following the transition into adult services [3,4].

Common mental health problems often go undetected in YP, with only 50% of adolescents in need seeking help [11,12]. These data are concerning; physical health outcomes in YP have been found to be exacerbated by psychosocial stressors, and recent findings of an interaction between psychological distress and medication non-adherence in YP post liver transplant. [9,10]. There is therefore an urgent need to develop service models which effectively address YP's 'medical, psychosocial and educational/vocational needs' in an integrated way in routine health care settings [1]. Effective transition between paediatric and adult care, including timely identification and intervention for mental health problems has a major impact on long term outcomes for all patients with a long-term medical condition [10, 30].

The Liver Transition Service at King's College Hospital aims to meet the needs of YP aged 16-25 years by providing developmentally appropriate multi-disciplinary care [13]. YP have access to the multidisciplinary team as needed and can remain with the service until fully transitioned into adult services. The team includes a core team of: paediatric and adult physician, specialist nurses, social workers and a clinical psychologist (covering ages 12-25 years). The service offers outpatient care and support with inpatient admissions. From its inception in 2008 until 2013, 458 patients were referred to the service with 931 recorded patient visits over the last year.

To successfully target interventions and focus limited resources within a busy clinic setting, it is essential that a YP's psychosocial needs are identified. To aid this, the service has introduced the use of an informatics system that facilitates routine collection of patient-reported outcomes, with real-time feedback to guide clinical care. These electronic mental health screening measures are completed in the waiting room, prior to patients' clinic appointments and provides instant alerts to the reviewing clinician regarding likelihood of depression/anxiety, as well as suicide alerts. Patients are then seen by the physician, who completes a complementary psychosocial screen (HEEADSSS). [14] The use of mental health screening measures in physical health clinics is recommended by The National Institute of Clinical Excellence (NICE), [15,16] and this electronic screening system has been found to be feasible and

acceptable within an adult general hospital setting. [17] However, this has not yet been evaluated in YP.

The aims of this paper are to: 1) Describe an integrated model of physical and mental health care for YP with liver disease and liver transplant; 2) Evaluate the feasibility and acceptability of implementing electronic mental health screening as part of routine care; 3) Evaluate the effectiveness of the screening in correctly identifying anxiety and depression in YP with liver disease and liver transplant.

METHOD

Participants

The liver transition service sees YP aged 16-25 years old (median 18 years) who have a range of different chronic liver diseases or following liver transplantation. These include conditions diagnosed in infancy (e.g. biliary atresia), childhood or adolescence (e.g. autoimmune liver disease). All patients attending the outpatient clinic are invited to complete screening measures as part of routine clinical care. The sample was screened between November 2013 and September 2015. This paper reports on the same cohort described in the authors' recent paper on self-reported rates of anxiety and depression. [8] To assess the implementation of electronic screening as part of routine practice, there were no exclusion criteria.

Procedure

YP were screened using the Integrating Mental and Physical Healthcare: Research, Training and Services (IMPARTS) web-based screening system. [17] Prior to their clinic consultation, YP were approached in the waiting room and given an information sheet by a volunteer, explaining the purpose of screening. The YP then completed a set of measures on an electronic tablet. The results upload immediately to their electronic health record for the clinician to review and discuss in their appointment, during which the HEEADSSS psychosocial screen would also be completed. [14]

IMPARTS has been granted ethical approval (NRES Ref: 12/SC/0422) to use pseudonymised data for research purposes. This study also received approval from the patient-led IMPARTS research oversight committee.

Measures

Patients completed outcome measures, including the: PHQ9 [18] and GAD7 [19] to measure depression and anxiety respectively. The outcome measures also include the Brief Illness Perception Questionnaire (BIPQ; [20]), a modified distress thermometer and adherence self-report measure. [8] As the focus of this paper is on evaluating the service model, only outcomes in relation to depression and anxiety are included. A short feasibility and acceptability evaluation was conducted with the first 53 patients who completed screening.

- Depression

The PHQ9 [18] is recommended by the National Institute for Health and Care Excellence (NICE) for measuring depression in physical health populations. [15] It has good sensitivity, specificity and test-retest reliability, [21] is well validated in medical settings, [22] and has similar psychometric properties in adolescents. [23] Both primary and secondary care mental health services use the PHQ9, enabling continuity of screening across services. Diagnostic criteria for probable major depressive disorder (pMDD) is met when the patient endorses 'more

than half the days' or 'nearly every day' on either question 1 or 2 (low mood anhedonia) plus four or more of the other symptom items. Question 9 (suicidal ideation) contributes to criteria if scored at 'several days' or more. Patients who did not endorse item 1 or 2 did not receive the rest of the questionnaire and were categorised as having 'no symptoms'. Patients who endorsed item 1 or 2 but did not meet the other criterion for pMDD were categorised as having 'some symptoms'. This accepted algorithm has good sensitivity (83%) and specificity (90%) for detecting pMDD. [22]

- Anxiety

The GAD7 can be used to provide a provisional diagnosis of Generalised Anxiety Disorder and assess symptom severity. [19] Diagnostic criteria for pGAD is met where the total score is 10+ (out of 21). [19] The GAD7 has good psychometric properties with good sensitivity, specificity and test-retest reliability including use in primary care patients and medical specialties across primary and secondary care. [19,24]

Psychosocial functioning

The HEEADSSS is a semi-structured psychosocial interview, designed for use by non-mental health clinicians as part of routine adolescent health care. [25] It represents different areas of exploration, with additional items having been added to the interview over time to recognise the changing social world of YP. The most recent version [14] encourages questioning around: Home life, Education and Employment, Eating, Activities, Drugs, Sexuality, Suicide/Mood and Safety (HEEADSSS). Clinicians are encouraged to use non-judgemental, open-ended questions within these topics to gain an overview of the YP's psychosocial world, including any strengths and concerns, and can provide invaluable information for engagement, wellbeing, and for improving illness self-management. The HEEADSSS is completed in every liver transition clinic appointment.

Feasibility and Acceptability

A feasibility pilot was conducted over the first 16 clinics in which electronic screening was introduced. The time taken to complete screening was recorded, and upon screening completion patients were approached by an assistant psychologist and asked to complete a 4-item questionnaire to capture their experience of screening or reasons for non-completion.

Outcome of screening

After screening, the physician reviews results via their electronic patient record which provided automated referral advice based on scoring algorithms and care pathways agreed by the clinical team. For patients meeting criteria for pMDD and/pGAD, a referral to the team clinical psychologist was advised. This was presented as guidance only; the clinical team decided whether a referral was appropriate based on discussion with the patient, their clinical judgement and considering any current psychological support the patient may have be receiving. If a referral was made, the patient was assessed by the clinical psychologist, typically on the same day as part of the multi-disciplinary clinic. At this point, a range of treatment/referral options may be offered; including a one-off session, further intervention, or referral to a local mental health service and/or to another professional within the team.

Effectiveness of Screening

At the end of the study period patient records were reviewed to document which patients received a referral to the team clinical psychologist from clinic on the days when screening took place. This was cross-referenced with the referral guidance generated by IMPARTS to assess and the level of agreement between this and clinical judgement.

RESULTS

187 patients (53% female) were screened during the study period, representing a mean age of 18 years (range 15-23 years). Patients had a variety of chronic liver conditions including biliary atresia (n = 35), autoimmune liver disease (n=72), alpha-1-antitrypsin deficiency (n=10), non-alcoholic fatty liver disease (n=6) and Wilson's disease (n=6). 51 YP (27%) had undergone liver transplantation.

Table 1. Time taken and patient feedback on the acceptability of screening

	Scale	**Mean (range)**
Time to complete screening*	Minutes	6 (2-15)
Q1) How did you feel about being asked to complete these questionnaires?	0 (Unacceptable) to 10 (Very acceptable)	8.9 (0-10)
Q2) How did you find the experience of completing these questionnaires?	0 (Negative) to 10 (Positive)	8.5 (0-10)
Q3) Would being asked to complete these questionnaires affect how you feel about coming to clinic?	0 (No, not at all) to 10 (Yes, very much)	1.2 (0-10)
Q4) How would you feel about being asked to complete these questionnaires every time you came to clinic?	0 (Unhappy) to 10 (Happy)	6.6 (0-10)

**Time taken for the complete battery; this included the PHQ9, GAD7, BIPQ, distress thermometer, adherence questionnaire, alcohol use and smoking*

Feasibility and acceptability

82% of patients attending clinic on a day where screening was available participated, with no differences between those screened/not screened in terms of age, gender or transplantation. [8] The most common reasons for non-completion were insufficient time before their appointment and problems with Wi-Fi connectivity. 53 patients participated in the feasibility pilot (table 1). Completing all 7 questionnaires took an average of 6 minutes. YP reported that they felt that completing screening questionnaires in this manner was acceptable, that they had a positive experience of it, and that routine screening would not affect the way they felt about coming to clinic.

Effectiveness of screening

17.7% of the total sample self-reported pMDD or pGAD. [8] The pathway for all YP included in this paper is shown in Figure 1. Level of agreement between screening and clinical judgement is shown in Table 2. The pathway and methods of clinical judgement demonstrate the fully integrated nature of mental healthcare within the service and the shared responsibility for this by all team members.

Table 2. Level of agreement between positive screen and clinical impression of clinically significant distress

Method	**Agreement with IMPARTS**	**False Positive**
Clinical Interview by CP*	14	0
Review of documentation by CP (e.g. from mental health service)	11	0
Clinical Interview by Physician and consultation with CP	5	2
Total	31	2

*Conducted either as a screening assessment in clinic or as part of ongoing therapeutic work

DISCUSSION

Depression and anxiety are prevalent in YP, elevated in those with LTC, and have been linked to poorer physical health outcomes via increased rates of non-adherence to medication and disengagement from services. [1,6,7]. The timely detection of common mental health problems is therefore an important part of good adolescent physical health care, and associated with improved physical healthcare outcomes [10,30]. The first step of integrated mental and physical health care is the identification of patient need.

This evaluation of a novel model of service delivery demonstrates that electronic mental health screening with real-time upload to medical notes, facilitates the identification of common mental health problems as part of routine adolescent physical health care. In line with the findings of a feasibility study in an adult general hospital setting [17], our study demonstrates that this system is also accessible, feasible, acceptable and an effective means of identifying common mental health problems in YP with chronic physical illness. Clinician judgment agreed with the presence of anxiety and/or depression in 31 of the 33 YP who screened as positive, suggesting that the screening platform can be used to facilitate the identification of common mental health problems in a physical health setting, in a time and cost-effective way.

Within our service, embedded psychosocial professionals ensured mental health difficulties were managed as part of routine liver care. Most of the YP screening positively for mental health problems were seen by the team psychologist or social worker as part of their attendance at the same clinic (i.e. during or following their appointment with the medical consultant). In addition to timely input from a mental health professional within clinic appointments, YP are

likely to have benefited from being cared for by a medical team trained in first-line psychosocial assessment, capable and confident in psychosocial assessments. The team's experience is that this integrated approach also ensures that co-occurring difficulties are managed in a complementary way. For example, the multidisciplinary team having a shared understanding of the relationship between a YP's depression, adjustment to illness and adherence behaviours, and subsequently working together to improve these concurrently.

Notably, the liver team members adopt a non-judgmental approach to the routine assessment of both adherence to immunosuppressive medication, and mental health. It is possible that this may have facilitated disclosures, and may have positively impacted on the reliability of self-report in this setting. [13] YP reported positive experiences screening within routine care, illustrating the need for all clinicians caring for YP with physical health conditions to assess broader psychosocial issues in routine clinical care.

With appropriate modifications, the method of electronic screening used in our study could also be piloted in adolescent teams which do not have embedded mental health clinicians. Care pathways would need to incorporate the use of local health care providers (such as Child and Adolescent Mental Health Services, Community Adult Mental Health Services, and Primary Care Counselling and Emotional Well-being Teams) and General Practitioners to activate referrals to local mental health services. This system could also be implemented within general adult services to improve care for younger people, and would translate well to an insurance-based health care system, such as those used in the United States.

However, it is important to highlight that the mental health screening did not effectively identify all YP that warranted psychosocial input; discussions in clinic appointments based on the HEEADSSS interview identified many other YP with additional needs that benefitted from psychological input, including other mental health problems (e.g. eating disorders, post-traumatic stress disorder), adjustment to illness, and intentional medication non-adherence. Aspects such as poor psychological adjustment to condition are highly pertinent for the physical health outcomes of this group [9] and are not necessarily detected by mental health screening alone. Other psychosocial difficulties were identified warranting referral to multidisciplinary team members: YP struggling with housing and finances see the team's social worker; YP struggling with diet see the dietician; and those having difficulties around sexual health are referred to a named sexual health physician within the same hospital. This emphasises the importance of both tailoring the battery of screening measures to the specific population needs, and the need for screening to be conducted in addition to appropriate clinical assessment and intervention, rather than in isolation. [26]

Further analyses of the psychometric properties of the PHQ9 and GAD7 in this specific population would be useful, given that not all patients who screened positive were considered appropriate for a psychosocial referral. These measures have been shown to have appropriate sensitivity and specificity amongst adolescents, [27] but sensitivity of the outcome measures may require further consideration in this chronic illness population. Inclusion of an additional screening tool, such as the Hospital Anxiety and Depression Index (HADS; [28]) would allow comparison of its performance against the current tools (PHQ9/GAD7). It is also of note that the screening outcome was not measured against a gold standard diagnostic interview, as this would not have been feasible in the clinic setting. However, a strength of this study is the integration of a screening platform into routine clinical practice in a pragmatic way, and utilization of a Clinical Psychologist's judgement as an adjunct to the standardized measures used.

Planned future work includes evaluating the sensitivity of an enhanced questionnaire battery to identify broader difficulties, and the relationship between these difficulties and self-

management skills, (non)adherence and physical health outcomes. This should include valid ways of identifying social difficulties as well as mental health and adjustment. Outcome studies are also needed to ascertain the effectiveness at psychosocial interventions for these difficulties in this population, and their impact on transition outcomes. [29]

In conclusion, this study shows that i) integrated and collaborative care is essential for adolescents and young adults with physical health problems throughout the transition period, ii) electronic mental health screening is a feasible, acceptable and effective way of integrating mental health care for this age group, and iii) that electronic screening alone does not replace the need for the physical health clinician to address psychosocial experiences of illness within their consultation nor the need for dedicated mental health professionals within physical health settings.

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